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Supportive care needs and psychological complaints among Mexican breast cancer patients

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CHAPTER

General introduction

- *"I felt blocked. I could not assimilate everything the doctor said. I feel confused just thinking about all the things that are going to change in my life. Why to me? I am only 28 years old"*
- *"I will get ahead. I will be calm because I want to live for my son"*
- *"I am worried about stopping working because of treatments and stop receiving my salary"*
- *"I tell myself that I have to be calm in order to schedule my appointments. I feel confused, worried and afraid because I do not know what they will do to me in chemotherapy"*
- *"I feel very confused, I did not expect this news, they also sent me to do many tests and they never explained to me the purpose..."*

Above are the reactions of five Mexican women after hearing the breast cancer diagnosis. The psychosocial implications of breast cancer have been extensively explored among Western patients, but there is a lack of empirical studies addressing these repercussions among Mexican breast cancer patients. Overall, psycho-oncological research among Latin American cancer patients is scarce. It is, however, important to perform such psycho-oncological research in Latin America, as research in Western countries has shown that the way that cancer patients psychologically cope with and adjust to breast cancer plays an important role in their recovery process, wellbeing, and quality of life.^{1,2} Previous research has shown that anxiety and depressive symptoms are highly present among breast cancer patients after diagnosis and even after a year of finishing the medical treatments for cancer.^{3,4} Thus, it seems relevant to investigate the prevalence and evolution of these symptoms among Mexican breast cancer patients, as these symptoms might impair the recovery process of the patients.

Likewise, previous research indicates that facing breast cancer may trigger different supportive care needs among patients with different stages of disease and from diagnosis to after finishing treatments.⁵ Thus, the World Health Organization has recommended incorporating supportive care services within the healthcare systems, as a common practice to ease the adaptation, to improve the ability of effectively coping with the disease and, overall, to increase the quality of life of cancer patients.⁶

An important starting point to provide supportive care services is the assessment of patients' needs.⁷ This may give more information on the nature of the unmet care needs of the patients at the different phases of the disease trajectory. This information might serve to plan adequate supportive care services and to prioritize the use of resources, which is especially relevant in Latin American countries like Mexico with limited budgets allocated to health spending. Despite the recommendations mentioned above, in Mexico the healthcare delivered to cancer patients mainly focuses on treating the physical symptoms of the disease, leaving aside the psychosocial aspects. Furthermore, the incorporation of supportive care services into the Mexican healthcare system is not yet high priority.

THE PRESENT STUDY

The main purpose of this study was to investigate the psychological complaints and supportive care needs of Mexican breast cancer patients from diagnosis to the first medical follow-up visit, after finishing with the primary treatments. We also aimed to explore indicators of the patients' coping abilities, specifically, perceived personal control and affective forecasting accuracy of the patients. We specifically addressed these research questions:

1. What is the prevalence of anxiety and depressive symptoms among Mexican breast cancer patients after hearing the diagnosis? (**chapter 2**)
2. How anxiety and depressive symptoms develop over the disease trajectory? Does perceived personal control might be a relevant predictor of changes in these symptoms, besides other characteristics of the patients? (**chapter 3**)
3. What are the main supportive care needs among Mexican breast cancer patients after the diagnosis? (**chapter 4**)
4. What is the course of patients' supportive care needs over the disease trajectory? And which characteristics of the patients might predict this course? (**chapter 5**)
5. Do patients accurately predict their positive and negative affect regarding their first medical treatment? Does affective forecasting accuracy of the patients make a difference in their psychological care needs? (**chapter 6**)

To answer these research questions, we set up a collaboration with the Gynecology and Obstetrics Hospital from the National Medical Center "La Raza", part of the Mexican Institute of Social Security (IMSS in Spanish) and the faculty of Psychology from the National Autonomous University of Mexico (UNAM in Spanish), in Mexico City. We first conducted a cross-sectional pilot study with a sample of 100 Mexican women newly diagnosed with breast cancer (**chapter 2**). Subsequently, a longitudinal observational study with a new sample of 174 patients was performed (from **chapter 3** to **chapter 6**). The design of the longitudinal study can be seen in figure 1. In the next two sections of this chapter we provide details about the Mexican context and elaborate on the psychosocial issues investigated in this study.

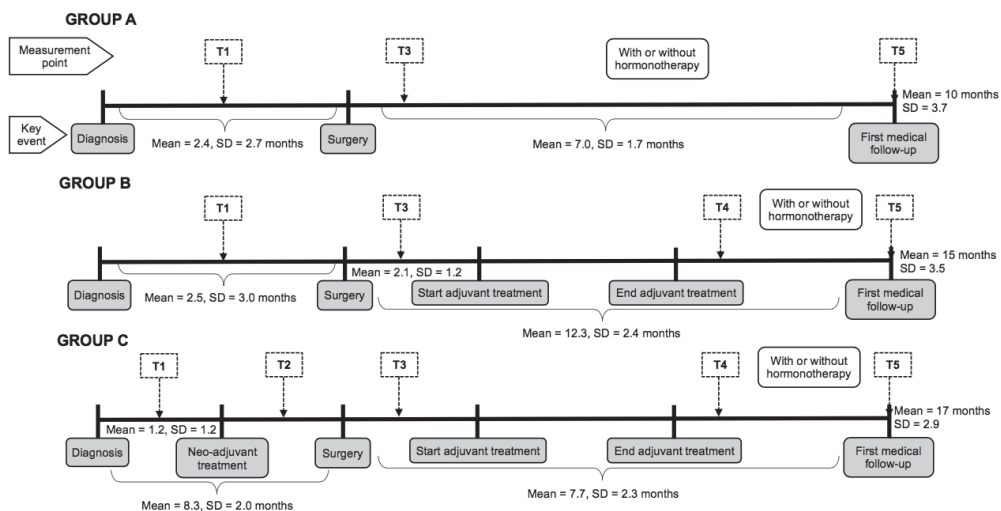


Figure 1. Design of the study

PART I. CONTEXTUALIZING: BREAST CANCER FIGURES AND THE MEXICAN HEALTH SYSTEM.

Prevalence, incidence, mortality and survival.

Breast cancer is the most prevalent form of cancer with the highest incidence among women worldwide. Over 17 million women worldwide suffer some type of cancer, 36% of them are breast cancer patients. Although, prevalence rates are a little higher in Western Europe countries and North America, 43% and 41% respectively; in Latin America and the Caribbean still 37% of women with cancer suffer from breast cancer.⁸ In Mexico, the prevalence of breast cancer cases in women with cancer is about 34%, according to the International Agency for Research on Cancer.

Incidence figures show that among the women who are diagnosed with some type of cancer over the world, 25% of these women receive a breast cancer diagnosis. Also, incidence rates are a bit higher in Western Europe countries and North America, 32% and 30% respectively, than in Latin America and the Caribbean, where 27% (152 059 new cases) of women diagnosed with cancer are diagnosed with breast cancer.^{8,9} However, it is expected that incidence will increase in the upcoming years in Latin America and the Caribbean.¹⁰ It is projected that by 2030 there might be an increase of 70% (224,000 new cases) in female breast cancer incidence, specifically, in Central and South America, considering demographic changes such as population aging and growth.¹¹ The lack of a national cancer registry makes difficult to get incidence trends in Mexico, but global cancer statistics on breast cancer reported an incidence of 25% for Mexico.^{8,9}

Regarding mortality rates, over 3 million women worldwide die from cancer, 15% of them died from breast cancer. While in high-income countries mortality rates have decreased, in low-middle income countries breast cancer mortality is rapidly increasing.¹¹ For instance, in the Central and South American region, mortality rates are rising in countries like Cuba and Brazil. Yet, Argentina and Uruguay remain having the highest mortality rate.^{11,12} Particularly in Mexico, in 2006, breast cancer replaced cervical cancer as the leading cause of cancer mortality among Mexican women.¹³ The trends on breast cancer mortality showed that there was an increase of around 42% from 1990 to 2013, although population growth contributed with 36%.¹⁴

Nowadays, thanks to the development of public health policies on early detection, prevention and control, as well as improvements in screening methods and medical treatments, survival rates for breast cancer have improved specially in high-income countries. According to the most recent report on cancer survival statistics worldwide (CONCORD-3), up to 89.5% and 90.2% of breast cancer patients diagnosed between 2010 and 2014, survived five years or more after diagnosis in Australia and USA, respectively.¹⁵ Nonetheless, wide disparities in the breast survival rates remain between countries. The CONCORD-3 study included data on nine Latin American countries. This report showed that Costa Rica reported the highest 5-year survival rate (87%), while Colombia had the lowest (72%). Survival data on breast cancer for Latin American countries is still scarce because of the lack of national registries. Breast cancer survival rates among Mexican women, come from isolated studies. A recent study with 4,300 Mexican breast cancer patients treated between 2007 to 2013 at the National Institute of Cancer (INCAN in Spanish), reported a 5-year survival rate of 82%, increasing to 97% for patients with an early-stage of the disease, remaining in 82% for patients with a locally advanced stage, and declining to 36% for patients with metastasis.¹⁶

Structure of the Mexican health system.

The Mexican health system follows a segmented structure and comprises two main sectors, public and private. Within the public sector are (a) the social security institutions (IMSS, ISSSTE, PEMEX, SEDENA and SEMAR) that provide health services to salaried workers within the formal sector of economy, and (b) the programs that provide health services to the population without social security. The private sector provides health services to the population with payment capacity.¹⁷ Usually people working in the formal sector of economy (e.g. teachers, civil servants, members of the army, employees of formal companies and their relatives), are the public insured population and receive care from well financed federal institutions of social security. Contrary, non-salaried population of those working on the informal sector of economy (e.g. self-employed workers, street vendors, or unemployed and their relatives) are the uninsured population and rely on underfunded, state-decentralized institutions or on the poorly regulated, costly private

sector. This latter group of the population, unfortunately, comprised most of the people. The care they received was not comprehensive and they frequently paid out-of-pocket for medicines and basic services.¹⁸

Until the end of century twenty, the structure of the health system in Mexico was based on the employment status of people described above. In 2003 there was a reform in the General Health Law that allowed to implement the “Popular Health Insurance” program.^{18,19} This program is a public insurance scheme that offers universal access to a comprehensive package of personal health services (including breast cancer treatment) to all citizens. The main aim of this program was to reach a universal health coverage, allowing to over 50 million Mexicans, previously uninsured, to access health services with financial protection.¹⁸ Although the aim was achieved and about 53 million Mexicans were incorporated to the System of Social Protection in Health (SSPH) by 2012, there was still around 29% of population without social protection of health.¹⁷

The challenge of breast cancer for the Mexican health system

Besides the rise of breast cancer mortality in Mexico, other factors that represent a challenge for the Mexican health system are the low mammography coverage, the poor quality and limited access to diagnosis and treatment, the limited budgets for clinical care, the insufficient number of specialized and qualified health professionals providing care to breast cancer patients, the delays in care-delivery, and the delayed patient presentation.²⁰⁻²² Specifically, the latter factor might be linked to the high rate of women that are diagnosed in advanced stages of breast cancer, which adds to the challenges that the Mexican health system faces. While in high-income countries most of the breast cancer patients are diagnosed in early stages of the disease, in Mexico around 50% of Mexican women are diagnosed in advanced stages.¹⁶ To the previous challenges mentioned above, we should add the lack of information regarding the psychological implications of breast cancer among Mexican women, and the provision of high quality supportive care in public health institutions.

PART 2. PSYCHOLOGICAL ISSUES AND SUPPORTIVE CARE NEEDS.

Psychological complaints associated to breast cancer in Mexican women

Anxiety and depressive symptoms are two of the most common psychological complaints that have been widely investigated among cancer patients.^{4,23} Nonetheless, empirical studies addressing these symptoms among Mexican women suffering from breast cancer are limited and generally of a low methodological quality (e.g. small sample sizes,

inclusion/exclusion criteria were not described, phase of the cancer trajectory at which patients were evaluated was not stated, convenience samples).²⁴⁻²⁷ Previous cross-sectional studies with Mexican breast cancer patients have evaluated anxiety and depressive symptoms among breast cancer patients receiving radiotherapy or chemotherapy,^{24,28} but there are no studies investigating these symptoms among the Mexican patients at the time of diagnosis. Thus, **chapter 2** focuses on the psychological impact of a breast cancer diagnosis among Mexican women, by evaluating their anxiety and depressive symptoms immediately after hearing the diagnosis. Subsequently, in another sample of Mexican breast cancer patients we examined the course of anxiety and depressive symptoms from diagnosis to shortly after finishing the treatments (**Chapter 3**), being the first longitudinal study on psychological complaints among Mexican breast cancer patients.

Psychological adjustment to cancer

The psychological coping and adaptation to breast cancer is generally linked to the patients' psychological characteristics, their social and economic resources, and the medical characteristics of the disease and treatment.¹ In the present study, we specifically investigated two psychological characteristics of Mexican breast cancer patients, the role of perceived personal control and affective forecasting accuracy.

Perceived personal control

Perceived personal control also known as mastery or locus of control refers to the people's perceptions about their ability to control the circumstances of their lives.²⁹ The role of perceived personal control in the psychological adjustment to cancer has been evidenced in several studies.³⁰⁻³³ Nonetheless, so far there are no studies addressing the role of perceived personal control among Mexican cancer patients. Because the meaning of perceived personal control might vary between individualistic and collectivistic cultures,³⁴ we considered relevant to examine the role of personal control in the psychological adjustment to breast cancer among Mexican women. Mexican culture is considered typically collectivistic and currently most of the studies on perceived personal control among cancer patients have been conducted on Western cultures typically considered individualistic. Thus, **chapter 3** explored the role of personal control in the course of anxiety and depressive symptoms among Mexican breast cancer patients.

Affective forecasting accuracy

Currently most of the research on psychological adaptation to cancer has focused on the evaluation of negative and positive emotions experienced throughout the disease trajectory.^{2,35} However, psychological adjustment to cancer is not only about experienced

emotions, but also encompasses cognitive processes. The people's ability to anticipate their emotional reactions to specific events in the future is one cognitive process that has been named affective forecasting.³⁶ Although predicting emotions might be potentially relevant in terms of adaption to a life-threatening illness,³⁷ so far affective forecasting has been little explored in the psychological process of adaptation to cancer. **Chapter 6** examined affective forecasting accuracy of Mexican breast cancer patients and its relation with their psychological care needs.

Supportive care for cancer patients in Mexico

In the last decades, there has been an increasing interest on care-related issues that is provided to cancer patients. We have evolved from curing the tumor alone to also caring for the patient and their families, that is, to comprehensive cancer care. This approach goes beyond providing only medical and physical treatment for cancer, as it refers to caring for the whole patient and meeting all his or her needs, using the services of a team composed by many specialized and qualified professionals working together.³⁸

Unlike high-income countries where this approach is being adopted in many healthcare institutions, comprehensive cancer care approach is lacking in most of the public hospitals from developing countries.^{39,40} Particularly in Mexico, there is not yet a supportive care approach to manage breast cancer treatment, there are no evidence-based guidelines to deliver supportive care, the availability of psychosocial services for cancer patients are limited, and there is a lack of public policies aimed to provide supportive care to Mexican cancer patients.^{41–43} Empirical research testing supportive care interventions among Mexican cancer patients is null.

Supportive care needs assessment in cancer patients

Supportive care is defined as the care provided along with the medical treatment at any point during the disease trajectory, aimed to prevent and manage the adverse effects of cancer and its treatment, thus, focusing on meeting the patients' psychological, spiritual, supportive, informational and practical care needs.^{44,45}

In order to incorporate supportive care services into routine care for cancer patients, the first step it is to evaluate the supportive unmet care needs that patients have when facing cancer. Extensive research on supportive care needs among cancer patients has been conducted mainly in Western and Asian countries,^{5,46,47} but the supportive care needs of Latin American cancer patients have been overlooked. Specifically, in Mexico research on supportive care needs of cancer patients is almost null; with the exception of one study among Mexican cancer patients,⁴⁸ there has not been previous studies addressing supportive care needs of Mexican cancer patients. Thus, the main aim of **chapter 4** was to investigate the supportive care needs of Mexican breast cancer patients after diagnosis.

Given the limited human and financial resources allocated to healthcare services within the Mexican health system,²⁰ it is important to identify the priority supportive care needs of the patients at each phase of breast cancer, as well as the characteristics of the patients that are in higher need of supportive care. Therefore, **chapter 5** examine how supportive care needs of Mexican breast cancer patients, identified in **chapter 4**, changed from diagnosis to shortly after finishing with the primary medical treatment and which characteristics of the patients predicted such changes. Previous longitudinal research on supportive care needs suggest that some breast cancer patients remain with low supportive care needs along the breast cancer treatment, while others show an increase or decrease in specific supportive care needs domains.⁴⁹⁻⁵¹ Thus, suggesting that not all breast cancer patients might require supportive care, and that there are specific domains in which supportive care is needed with higher priority. In the present study, we evaluated six dimensions of supportive care needs named health system and information, psychological, physical and daily living, patient care and support, sexual and practical care needs.

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*When you come out the storm, you won't be the same person
who walked in. That is what this storm is all about.*

- Haruki Murakami -

